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ABSTRACT

Topics addressed in this report were suggested at a meeting of staff from the National Center for Health Services Research and Health Care Technology Assessment (NCHSR) and other Public Health Service representatives held in 1988 to update the Public Health Service's plan for the prevention and control of human immunodeficiency virus (HIV). Current epidemiologic and economic information about Acquired Immune Deficiency Syndrome (AIDS) and other HIV-related illnesses is reviewed, highlighting the complexity of issues and gaps in knowledge that should be addressed in grant research. Priority research issues and examples of substantive research questions are presented. Issues are identified that extend beyond health economics and the costs and financing of services. Researchable topics are outlined with respect to health status measures and information systems, access and barriers to care, quality of care, health systems analysis, cost effectiveness of alternative service and organizational strategies, and provider issues. A general description of application procedures and a bibliography of relevant information are also provided. (NB)

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HIV-Related Illnesses: Topics for Health Services Research

October 1988

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Contents

Introduction 1
- Epidemiologic Issues 1
- Cost and Financing Issues 3

Priority Research Issues 4
- Cost and Financing of Care 4
- Health Status Measures and Information Systems 5
- Access and Barriers to Care 6
- Quality of Care 6
- Health Systems Analysis 6
- Cost Effectiveness of Alternative Service and Organizational Strategies 7
- Provider Issues 7

Application and Review Procedures 8

Selected References 9

Introduction

In 1986, the Public Health Service (PHS) published a plan for the prevention and control of human immunodeficiency virus (HIV). The plan advocated support for "health services research on AIDS that emphasizes cost of services for different risk groups, stages of illness, and treatment modalities, and assesses the potential improvements of methods and increased cost effectiveness of care." In 1988, staff from the National Center for Health Services Research and Health Care Technology Assessment (NCHSR) met with other PHS representatives in Charlottesville, VA, to update this plan; areas in need of health services research were discussed as part of this update.

In addition to emphasizing the need to conduct cost analyses, the recent Charlottesville meeting called for studies that focus on the cost effectiveness and financing of care for illnesses related to HIV. Broadening the scope of health services research beyond the economic issues was recommended. Examples are developing health measures and informational systems for HIV-related care, analyzing barriers to care, investigating HIV-related health systems, examining organizational characteristics associated with effective service delivery, and exploring issues of importance to health care professionals who work with patients infected with HIV or suffering from an HIV-related illness.

As part of the Public Health Service, NCHSR has been asked to investigate ways to add to existing knowledge on health services research in HIV-related illnesses. In response, NCHSR is interested in the study of health services research issues on the availability, cost, and utilization of services for different HIV risk groups, populations, geographic areas, stages of illness, and treatment modalities. Other topics include the financing of services for AIDS and the effects of the disease on the organization and management of health care services.

Reviewed here is current epidemiologic and economic information about AIDS and other HIV-related illnesses that highlights the complexity of issues and gaps in knowledge that should be addressed in the grant research. Priority research issues and examples of substantive research questions are presented. Issues are identified that extend beyond health economics and the costs and financing of services. Researchable topics are outlined with respect to health status measures and information systems, access and barriers to care, quality of care, health systems analysis, cost effectiveness of alternative service and organizational strategies, and provider issues. A general description of application procedures and a bibliography of relevant information are also provided.

Epidemiologic Issues

The epidemiology of HIV-related illnesses involves analysis of variations in the patterns of disease across major sociodemographic groups, risk groups, and geographic areas. Variations in the patterns of disease affect the cost-effective delivery of health care, challenging the organizational, management, and financial capabilities of the health care system. While much of the current information on HIV-related illnesses is limited to AIDS, it is important to examine the implications of all HIV-related illnesses for the organization, delivery, and financing of health care services. In addition to presenting a discussion of the present and future scope of the disease, and its sociodemographic and geographic variations, this section will highlight definitional complexities that affect health services research on HIV-related illnesses.

According to the Centers for Disease Control (CDC), over 72,500 confirmed cases of AIDS and over 36,000 deaths from AIDS have been reported (CDC, 1988b). Recent evidence suggests that the average time from contraction of HIV to clinical manifestation is approximately 7.8 years (Liu and others, 1988). Discussion at the Charlottesville conference in 1988 indicated that between 1 and 1.5 million persons are currently infected with the HIV virus. Some project that as many as 750,000 persons may be diagnosed as having CDC-defined AIDS by 1991 (Pascal, 1987). However, the most recent PHS projection, as reported at the Charlottesville conference (1988), is approximately 365,000 confirmed cases of AIDS by 1992, with approximately 80,000 new cases expected in 1992. Specter (1988) has estimated that there will be as many as 100,000 new cases in 1993.

The proportional distribution of persons with AIDS (PWAs) across risk groups is changing. As of January 1987, 65 percent of all cases were homosexual/bisexual men; 17 percent were intravenous drug abusers (IVDAs); and 8 percent were homosexual/bisexual men who also use drugs (CDC, 1987). While homosexual/bisexual men still comprise 63 percent of all cases reported, incidence of newly reported cases within this group has declined. Only 57 percent of newly reported cases since January 1988 were homosexual/bisexual. In contrast to this, IVDAs now comprise 19 percent of all cases and 24 percent of cases reported since January 1, 1988. Stability of cases across remaining risk groups continues: 7 percent of all cases occur in homosex-

ual/bisexual men who use drugs; 4 percent in transfusion recipients; 4 percent in high-risk heterosexuals (those having multiple sex partners or partners from other risk groups); and 3 percent in patients with no identifiable risk (CDC, 1988b).

The number of cases of AIDS from minority groups is disproportionate to their representation in the general population. Eighteen percent of all persons in the United States are black or Hispanic, but these groups comprise nearly 41 percent of all HIV-related cases. Furthermore, 73 percent of female cases and 76 percent of pediatric cases are found among these minority groups (CDC, 1988a).

As of June 1988, over 5,000 PWAs were reported among women. Women comprise nearly 8 percent of all cases, an increase of 33 percent since 1981. The major cause of infection among women is intravenous drug use (52 percent of all cases in 1986). The rate of infection among women with AIDS due to heterosexual contact has increased from 14 percent in 1982 (Guinan and Hardy, 1987) to 29 percent in 1988 (CDC, 1988a). The potential for infection through heterosexual transmission and the disproportionate representation of female cases among minority groups have serious implications for the planning and allocation of health resources.

Although the total number of AIDS pediatric cases (under 13 years of age) through the end of May 1987 was approximately 1,000, the Surgeon General has estimated that between 3,000 and 5,000 infants have been born with the disease to date (Bibisi, 1987). Seventy-eight percent of pediatric cases have involved children with one or both parents at risk for AIDS, the great majority of whom were IVDAs (CDC, 1988b).

Risk groups vary by race. For example, 78 percent of all white, non-Hispanic cases are homosexual/bisexual men, and only 6 percent are strictly IVDAs. However, among blacks and Hispanics, AIDS cases are approximately evenly distributed between homosexual/bisexual men and IVDAs (CDC, 1988b).

Geographic variation in the distribution of AIDS cases is occurring. Before 1984, over half of all cases were found in New York City or San Francisco. This proportion has now fallen to about 28 percent of all cases reported in 1987 (CDC, 1988a).

Regional variation is also found among risk groups. In San Francisco, the disease is found largely in the homosexual population—97 percent of those afflicted are homosexual (Scitovsky and Rice, 1986). In contrast, PWAs in the New York City population are often drug abusers—37 percent are IVDAs (nearly 84 percent of these are known heterosexuals), and 44 percent are homosexual or bisexual men. Also, 57 percent of PWAs in New York City are black or Hispanic. These two groups constitute 82 percent of all IVDAs (New York City Department of Health AIDS Surveillance, 1988).

Although the above data provide an indication of the variation in the distribution of HIV-related illnesses, a problem in estimating the extent and distribution of the HIV epidemic arises from changing disease definitions. In August 1987, the CDC expanded the definition of AIDS to include persons in high-risk groups with related ailments such as dementia and wasting syndrome. Currently, it is estimated that 10 percent of all cases reported since the change in definition are attributable to these two conditions (personal communication, W. Meade Morgan, CDC, 1988).

Several efforts to develop systems for the staging and severity of HIV infection have been undertaken. The CDC developed a four-group classification system for HIV-related illnesses, which is currently in use. Gradations range from the presence of transient signs and symptoms that appear after demonstration of seropositivity, to clinical manifestations of constitutional disease, neurologic disease, secondary infectious diseases, selected cancers, and/or other conditions. This classification is hierarchical and useful only for epidemiologic studies. Researchers from NCHSR and from Jefferson Medical College have developed a staging system for AIDS hospitalizations (Turner and others, 1988). The Walter Reed Army Institute of Research has also developed a six-stage classification system applicable to adults (Redfield and others, 1986).

The variations in the course of the disease compound the difficulties inherent in developing staging and severity indices of HIV-related illnesses. *Pneumocystis carinii* pneumonia (PCP) is the most prevalent opportunistic infection, occurring in 61 percent of all PWAs. Kaposi's sarcoma (KS) occurs in 10 percent, and other opportunistic infections are found in 29 percent. Cases reported since January 1, 1988 indicate a decline in PCP (54 percent) and KS (6 percent), and an increase in other opportunistic infections (40 percent). Furthermore, different populations display different manifestations of the disease. For example, the CDC estimates that KS occurred in approximately 27.3 percent of homosexual/bisexual men with AIDS since 1981, compared with 2.9 percent of IVDAs with AIDS (Selik and others, 1987).

Disease definition, staging, and severity have tremendous implications for assessing both the cost and effectiveness of providing health care for those with HIV-related illnesses. They are of further importance in assessing variations in the delivery and financing of health care measures across risk groups, populations afflicted, and geographic areas.

Cost and Financing Issues

The focal point of health services research on HIV-related illnesses has been on the cost and financing of health care services for PWAs. Estimates of the cost of treating a PWA have been reported, ranging from a low of $27,571 lifetime hospital costs (1984 dollars) in one San Francisco study (Scitovsky and others, 1986), to a high of $147,000 based on an extrapolation of the first 10,000 cases reported in the country (Hardy and others, 1986). Scitovsky and Rice (1987) estimated that the average national lifetime cost in 1984 dollars ranged from $60,000 to $75,000. Hellinger (1988) estimates treatment costs in 1988 to be about $57,000 (in 1985 dollars) rising to about $61,000 in 1991, mainly due to the increasing use of azidothymidine (AZT).

Many limitations of previous cost studies stem from their retrospective focus on a disease that is rapidly evolving in terms of definition, epidemiology, and treatment. Cost studies rely mainly on inpatient treatment costs. In addition to wide regional variations in the average daily hospital charge for an HIV patient (i.e., approximately $1,000 per day in Alabama and Illinois compared with under $550 in Maryland, as reported in Scitovsky and others, 1988), there is even greater variation across treatment settings. One report noted that an average daily hospital charge in San Francisco General Hospital approximated $700, compared with $300 a day for long-term care and $100 a day for home care (Burda and Powills, 1986). Some forms of treatment may be more cost effective than others. Although treatment setting can be expected to vary by patient need, little is known about the availability of low-cost care, the types and costs of community support services needed to provide it, and the relative quality of less expensive care.

It appears that the locus of care may be shifting to the outpatient sector. Previous research indicated approximately 10 percent of all health care costs were concentrated in the ambulatory sector (Kizer, 1987). More recent data suggest that it may be as high as 30 percent (Scitovsky and others, 1988).

Another limitation of cost studies stems from the case definitions utilized in previous research. All current estimates are based on a restrictive definition of AIDS, which does not encompass cases identified through the expanded definition of the CDC (Hellinger, 1988). Also, only a few studies have examined the costs associated with other HIV-related illnesses. For example, Kizer estimated the cost of the illnesses comprising the syndrome of AIDS-related complex (ARC) to be approximately 27 percent of the monthly cost of treating AIDS (Kizer, 1987).

Additional constraints have clouded the estimation of the costs and financing for HIV-related illnesses. Most studies conducted to date have limited geographic scope and pertain mainly to homosexual/bisexual men. Small sample size, inadequacies in existing data systems, confidentiality restrictions in data acquisition, and the unwillingness of patients to participate in studies have further limited current work.

Expenditures for the treatment of HIV-related illnesses may also vary markedly as new treatments become available. Currently, AZT is the only FDA-approved, antiviral drug available for the treatment of AIDS. It costs an average of $8,000 per patient per year, although estimates range as high as $10,000-$20,000 annually (Specter, 1987, 1988). While AZT may prolong life for some AIDS patients by several months, its serious side effects may actually raise treatment costs (Hellinger, 1988). However, this may be partially offset by potential gains in income and productivity, as well as the reduced occurrence of opportunistic infections and reduced need for hospital care (Pascal, 1987).

Some extrapolations from current costs have yielded projections that the estimated $1.1 billion in direct costs for treating PWAs in 1986 (0.3 percent of total personal health care expenditures) will increase to between $4.5 billion (Hellinger, 1988) and $8.5 billion (Scitovsky and Rice, 1987), or between .75 and 1.4 percent of all health care expenditures in 1991.

Indirect costs of AIDS, estimated at $3.7 billion in 1986, are expected to increase dramatically to $55.6 billion in 1991. This represents an increase from 2.1 to 12 percent of all indirect costs attributed to illness (Scitovsky and Rice, 1987). Income and productivity loss due to morbidity and mortality are likely to be a significant component of the total costs of AIDS and other HIV-related illnesses, particularly for the homosexual population affected. Better ways to estimate both indirect and direct costs of the illness are needed, given varying assumptions of the rate at which the disease spreads, definitions of the disease, and the availability of alternative treatment modalities.

There is little information on the sources of payment for the costs of HIV-related illnesses. At present, approximately two-thirds of daily hospital costs of AIDS are reimbursed by third-party payers (Burda and Powills, 1986; Pascal, 1987). Reimbursement can be expected to vary regionally by State, due to differences in both the availability and coverage of Medicaid for "medically needy" people. In addition, there are significant variations in the coverage of traditional insurance plans and in the availability of State risk pools.

The potential for variation exists in the use of insurance and employment screening for HIV-related illnesses, especially with regard to small-group and individual policyholders (Eden and others, 1988). As employers and insurers begin to screen for HIV-related illnesses, the fiscal burden of the diseases may increasingly be borne by the public sector. Attempts to waive or decrease the 2-year "waiting period" for PWAs under 65, allowing them to qualify for Medicare on the basis of disability, may succeed. This would significantly increase the public role in financing health care for AIDS patients. On the other hand, recent Consolidated Omnibus Budget Reconciliation Act (COBRA) legislation mandates employers of 20 or more persons to continue to offer former employees medical insurance coverage for 18 months after cessation of employment. Premiums would generally be paid by the former employee. This may help to provide some private support for PWAs forced to relinquish their jobs. However, as effective therapies are developed and patients live longer, the burden may shift back to the public sector.

Given the complexities noted above, estimates of the percentage of the AIDS population covered by Medicaid range from 7 to 65 percent, by private insurance from 7 to 13 percent, and by Medicare from 1 to 3 percent. Estimates of the uninsured AIDS population range from 2 to 40 percent (Sisk and others, 1987). There is no documentation of the extent to which unreimbursed care is subsidized by other patients or sources of payment. State and Federal sources of Medicaid account for 23 percent of payments for the illness, and it is estimated that 2.5 percent of the Federal Medicaid budget will be devoted to AIDS by 1991 (Sisk and others, 1987). Again, it is important to note that these estimates exclude the financing of other HIV-related illnesses.

The financial burden in underwriting the cost of HIV-related illnesses is shared among Federal, State, local, and private sources of payment. Informed policy requires data on the distribution of financial support and the effect of changes in reimbursement policy on the relative burden among various sources of payment.

Given the above discussions on the present and future epidemiologic configurations of the disease, the state of knowledge on the cost and financing of HIV-related illnesses, and their joint influence on the effective and efficient delivery of health care, NCHSR is interested in sponsoring health services research on the following issues dealing with HIV-related illnesses:

- Cost and financing of care
- Health status measures and information systems
- Access/barriers to care
- Quality of care
- Health systems analysis
- Cost effectiveness of alternative service and organizational strategies
- Provider issues

Priority Research Issues

Cost and Financing of Care

Health services research on HIV has focused on the costs and expenditures for treatment. Several restrictions have made it difficult to estimate current and future costs. Among the factors contributing to the difficulties in research on costs and financing are the following: newness of the disease, small sample sizes, confidentiality, data, and generally a lack of data availability for all but acute inpatient services provided to homosexual/bisexual men in certain geographic locations. The different types of population groups most affected by the disease make it very difficult to compute the indirect costs of HIV (i.e., the loss of income and productivity resulting from morbidity and mortality).

The cost and financing of treatment will also be affected by the expanded definition of AIDS, the possibility of new diagnostic techniques that are more sensitive and can detect the presence of the illness much earlier than conventional screening techniques, and the expanded use of AZT and other new treatments.

The following are examples of researchable questions related to the problems of estimating and measuring the cost and financing of HIV-related illnesses:

- What is the variation in costs of treating an episode of illness? Studies should (1) assess the entire duration of an illness and (2) address the wide spectrum of services used including inpa-

tient services, outpatient services, discharge planning, hospice care, long-term care, home care, community-based volunteer programs, psychiatric care, and support services. Wherever possible, such studies should distinguish costs from charges.

- How do costs for the treatment of HIV-related illnesses vary by region, risk factors, demographics (age, race, gender), and socioeconomic variables?
- What are the indirect costs of HIV-related illnesses? How do they vary for different treatments, types of services utilized by patients, and population groups affected?
- What are the projected costs (both direct and indirect), charges, and expenditures for HIV-related illnesses? How do these estimates vary with changes in assumptions concerning the extent of the disease, population groups affected, and treatment protocols used?
- How has the availability and coverage of insurance for HIV-related illnesses been affected by COBRA legislation, by use of screening for HIV infection by employers and insurers, by mandated insurance coverage for at-risk populations, and by employer self-insurance?
- What is the extent of unreimbursed care for HIV-related illnesses and seropositive individuals? How are these costs absorbed, especially in areas with high concentrations of uninsured or inadequately insured patients?
- How are various sources for the financing of HIV care projected to change in response to the anticipated rise in the number of patients and to changes in the types of patients, specific HIV-related conditions, and diagnoses? How is this expected to vary by geographic area?
- What impact do volunteer services have on access to health care services, quality of care, and financial burden for the individual and community? How do volunteer services vary by region?
- What are the most cost-effective prevention and treatment strategies? An example of an effectiveness measure is the amount of time actively engaged in work after diagnosis for those with HIV-related conditions.
- What is the cost effectiveness of providing precautions and training programs for personnel involved in the treatment of HIV-related cases?

Health Status Measures and Information Systems

In its recent report "Confronting AIDS," the Institute of Medicine of the National Academy of Sciences emphasized (1986) that "a sound data base is needed to ascertain the relative costs and effectiveness of inpatient hospital treatment, outpatient and home care, hospice care, and other types of health services." Research is needed to define the requirements of an information system for collecting data about the effects of the HIV epidemic on the organization and delivery of health care.

Information systems are needed to produce accurate, timely, and comprehensive data useful for health services research and policy analyses, for epidemiologic inquiries, and for clinical investigations. It will be necessary to collect or organize evidence from a wide variety of sources, and to support both descriptive and comparative investigations using longitudinal as well as cross-sectional study designs.

In addition, instruments specifically designed to measure the severity of HIV-related illnesses, treatment outcome, and functional status need to be developed and validated in order to accurately assess the effects of various types of organization and delivery of HIV-related services.

NCHSR is particularly interested in the following research issues and questions:

- The design of medical records systems to permit the confidential collection and aggregation of longitudinal, patient-specific data in order to develop severity indices, patterns of illness, health status measures, and analyses of practice variations.
- The development of recordkeeping systems that can acquire and integrate information from informal caregivers and organizations in order to produce more accurate and complete profiles of patterns of illness, effectiveness of caregiving methods, and distribution of social and economic burdens.
- The construction of data banks or registries in order to permit more accurate identification and comparisons of different practice patterns, more focused and efficient clinical and epidemiologic investigations, and more rigorous assessments of medical technologies.
- What are the effects of the HIV epidemic on policies and procedures in health care settings, such as changes in equipment re-use policies, tissue banking practices, waste disposal, or staffing requirements?

- How can better health outcome indicators, functional status measures, and measures of illness severity be constructed? Are there existing instruments for other diseases that can be adopted or improved?

Access and Barriers to Care

Access to care may be limited because patients with HIV-related illnesses may be more likely to possess no insurance or to require public assistance. This is because the debilitating nature of the disease often restricts employment opportunities, and because the disease is concentrated in some areas among relatively poor minority groups. This may restrict the number of providers who will care for these patients. Furthermore, the infectious nature of the disease may limit the willingness of providers to give appropriate and sustained treatment.

Researchable questions on access to care include the following:

- What services are available and used for the treatment of HIV-related illnesses (e.g., inpatient acute care, outpatient care, home health services, hospice care, long-term hospitalization, psychiatric care, and voluntary support services)? How do these vary by geographic area, risk group, severity of illness, and the nature of the disease?
- How do the types of available services and continuity of services used for HIV-related conditions vary by health care setting and the financing of care?
- How do variations in the availability of services, resource utilization, and continuity of services correlate with insurance coverage or minority and socioeconomic status? To what extent are these variations determined by patient versus health care practitioner decisions?
- How do barriers to care such as lack of insurance coverage and availability of health practitioners affect health care utilization (e.g., increased use of inpatient facilities, provision of less intensive medical care) and treatment outcome (e.g., mortality, episodes of illness, and severity of illness)?
- What are the community and individual factors that promote or hinder the establishment of HIV-related services (e.g., community resistance, individual attitudes, risk group most prevalent in the community, size of the community, and the availability of informal social support)?

Quality of Care

Many variables affect the quality of care provided to patients with HIV-related illnesses. These include the supply of practitioners and settings equipped to deal with the disease, the demand for treatment, and patient characteristics.

The nature and intensity of services provided to HIV patients are partly a function of patient prognosis. Published data indicate that 50 percent of PWAs die within the first year after diagnosis (Rothenberg, 1987); 75-100 percent are estimated to die within 2 years (Selwyn, 1986a,b,c; Rivin and others, 1984). Average life expectancy from time of AIDS diagnosis has been calculated at 13 months (Hardy and others, 1986; Moss and others, 1984; Scitovsky and Rice, 1987a, 1987b; Seage and others, 1986). More recently, unpublished accounts indicate that life expectancy may be approaching 2 years (personal communication, Dr. Debra Colten, Beth Israel Hospital, September 1988).

Among the questions on quality of care that need to be addressed are the following:

- What is the quality of care provided to patients with HIV-related illnesses? Quality of treatment may be defined by such measures as patient satisfaction, increased longevity, quality-adjusted survival, reduced pain, and the education of patients about their disease and options for treatment.
- What is the nature of patient/practitioner interactions? What is the effect of these interactions on patient compliance with treatment or prevention regimens, satisfaction, and functioning?
- How does patient preference influence treatment? How is patient preference weighed against concerns about cost containment, sources and burdens of payment, and reimbursement levels?
- How does the quality of care vary by regional prevalence of the disease, the supply and types of treatment settings, the practitioners who treat the disease, and the characteristics of patients (e.g., insurance coverage or minority and socioeconomic status)?
- What are the similarities and differences in various dimensions of quality of care between patients with HIV infections and patients with other types of terminal or chronic disease?

Health Systems Analysis

The AIDS epidemic is likely to have far-reaching effects on the distribution of health care resources; the organization and management of formal and

informal (community-based) health care delivery networks; and the detection, treatment, and financing of other diseases. There is a need for research on how the HIV epidemic affects the resources available to treat these other diseases. Much is already known from the study of other diseases about how to manage chronic/terminal illness (see Brandt, 1987; Eisenberg, 1986; Yankauer, 1988). Such knowledge could be useful in treating HIV-related illnesses. Conversely, the research and practical experience engendered by the HIV epidemic may yield new knowledge useful in the treatment of other diseases.

The following research questions concerning the impact of HIV-related illnesses are of interest:

- How have HIV-related illnesses affected the structure, functions, interrelationships, and fiscal viability of institutional- and community-based health care organizations?
- What are the similarities and differences in international experiences in the prevention, cost, financing, quality of care, and access to health care for those afflicted by HIV-related illnesses? How exportable are these experiences?
- What are the "spillover" effects of, and resource trade-offs between, HIV related illnesses and other illnesses in terms of the relative levels and type of resources available for the provision of health care services; the organization of health care; the financing of services; and their prevention, diagnosis, and treatment? What are the ethical issues involved in resource tradeoffs between HIV-related illnesses and other illnesses?

Cost Effectiveness of Alternative Service and Organizational Strategies

Given the rapidly changing clinical and epidemiologic profile of the disease, the health care sector has had little time to implement an appropriate response for the provision of services. The emergence of new treatment modalities and more sensitive screening mechanisms further complicates the task of planning for the care of HIV patients.

The identification of cost-effective ways for organizing, managing, and delivering health services to HIV patients is critical. Cost-effectiveness analysis, however, needs to distinguish costs from charges, consider severity of illness and quality of life, and use consistent measures of the relative effectiveness of different strategies for providing health care services.

Models for providing appropriate care to HIV-infected persons must take into account a multitude of factors. Effectiveness of services may vary by risk group, level of illness, existing resources, or reimbursement. No one type of organizational structure or treatment modality is likely to be effective for all patient types in every geographic area. The coordination of services may also be crucial for the cost-effective provision of care for HIV patients.

NCHSR is interested in studies that will explore the following issues:

- How do treatment and cost vary by organizational characteristics such as ownership, teaching status, size, concentration of HIV caseload, and integration in a multi-institutional health care system?
- What is the comparative cost effectiveness of centralization versus decentralization of service delivery at the facility level? Is the use of dedicated units in hospitals versus scattered beds a more cost-effective strategy?
- How has the HIV epidemic affected health care facilities with a large number of cases in terms of staffing ratios, personnel mix, and patient demand? How effective are strategies employed by these facilities to manage large numbers of HIV-related cases? What effects do varying concentrations of HIV patients have on facility operations and patient care?
- What are the sources of funding for medical, legal, mental health, and social support services provided by community-based, volunteer AIDS organizations, and how do they, in conjunction with organizational factors, influence the effectiveness of volunteer services? How are volunteer services coordinated with each other and with the formal health care delivery system? Do they provide services that are substitutes or complements to those of other organizations, enhance access and quality, and decrease costs? What is the potential for the expanded use and effectiveness of community-based volunteer organizations in dealing with HIV-related illnesses?

Provider Issues

The epidemic of HIV-related illnesses has engendered a number of concerns among providers. Potential provider exposure to the body fluids of patients necessitates greatly increased safeguards that may prove inconvenient and may increase reluctance to treat such cases. In addition, providers may hesitate to provide care to HIV patients who engage in substance abuse and homosexual activity. Moreover, these providers are treating persons whose prognosis is almost always terminal. All of these

issues have led to concern on the part of health care practitioners who are, or may be, treating HIV-related cases (see Link and others, 1988; Wachter, 1986) and may contribute to the professional "burnout" of these practitioners.

Some interesting questions in this area include:

- How are health care practitioners and volunteers (including informal homecare providers and unpaid personnel in formal and community organizations) reacting to the HIV epidemic in terms of their availability, turnover, willingness to treat HIV-related illnesses, and burnout from treating HIV victims? What are the financial and organizational factors affecting provider burnout?
- How informed are health care workers about the nature and treatment of HIV-related illnesses? How has information on the risk of professional contact and the education of practitioners on the nature and treatment of the disease affected the willingness of providers to treat patients with HIV-related conditions? What is the relative effectiveness of this information, with respect to increased patient satisfaction, availability of providers, treatment of patients, reduced costs of care, and decreased professional burnout?
- Does the ability to exercise discretionary judgment in the decision to treat HIV patients vary across employment settings and types of health care professionals?
- What is the effect of variations in the mix of health professional skills on the treatment of HIV-related illnesses? What is the most cost-effective mix for various treatment settings and population groups?
- How is the HIV epidemic affecting provider choice of specialty, choice of location, or other practice decisions (e.g., decision to retire)?

Application and Review Procedures

The extramural research program of NCHSR provides grant support for health services research authorized by section 305 of the Public Health Service Act (42 USC 242c). Grants are administered under the *Code of Federal Regulations*, 42 CFR part 67, and the Public Health Service *Grants Policy Statement*.

Applications may be submitted by any public or private nonprofit institution or unit of State or local government. Applications are to be submitted on Public Health Service Form 398, Grant Application, except for applications from State and local governments. The latter are required to submit Form DHHS 5161 Application for Federal Assistance (nonconstruction programs).

Application materials are available from

John D. Gallicchio
Chief, Review and Advisory Services Program
National Center for Health Services Research and Health Care Technology Assessment
Room 18A-20, Parklawn Building
5600 Fishers Lane
Rockville, MD 20857 (301/443-3091)

Application materials may be available from business, grants, and contracts offices of academic or research institutions, and also can be obtained from the National Institutes of Health (NIH), Division of Research Grants (DRG), whose address appears below.

The applicant should check the box on the application form's face sheet (line 2) indicating that the proposal is in response to this program note and print (next to the checked box) "NCHSR Program Note on Health Services Research and HIV-Related Illnesses." The applicant also should enclose a cover letter citing this program note.

The schedule for submission and review of applications on HIV-related illnesses is as follows:

NIH/DRG submission	Study section review	Earliest start date
June 1	October	December 1
October 1	February	April 1
February 1	June	August 1

The original and six copies of the application should be sent or delivered to

National Institutes of Health
Division of Research Grants
Room 240, Westwood Building
5333 Westbard Avenue
Bethesda, MD 20892

All NCHSR research grant applications are reviewed for scientific and technical merit by a review panel or study section comprised of non-Federal scientists. Each application will be reviewed by the appropriate NCHSR study section according to the following criteria:

- the significance and originality of the project from a scientific and technical viewpoint,
- the adequacy of the methodology proposed to carry out the project,

- the availability of data and the adequacy of the data collection plan,
- the appropriateness of the work plan and schedule for organizing and completing the project,
- the qualifications of the principal investigator(s) and staff,
- the adequacy of the facilities available to carry out the project,
- the reasonableness of the budget, and
- the adequacy of the proposed protection of human and animal subjects.

If the proposed projects on HIV-related illnesses are no more than 2 years in length and require no more than $50,000 in total direct costs for the entire project period, then these projects are eligible for accelerated review. Such projects intended for accelerated review must be sent directly to NCHSR (Room 18A-20). Because of a modified review process that involves both Federal and non-Federal experts, NCHSR is able to notify applicants of funding decisions within approximately 120 days. Deadlines for receipt of these applications at NCHSR are the first working day of the following months: January, March, May, July, September, and November.

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